

# Deaf lesbians, “designer disability,” and the future of medicine

Julian Savulescu

With the completion of the human genome project, the genetic basis of disease is becoming better understood. Genetic tests for disabilities are increasingly becoming available to allow couples with a family history of genetic disease to select healthy offspring. But some couples wish to select for disability. Might there be good reasons for acceding to such requests?

A deaf lesbian couple in the United States have deliberately created a deaf child. Sharon Duchesneau and Candy McCullough used their own sperm donor, a deaf friend with five generations of deafness in his family. Like others in the deaf community, Duchesneau and McCullough don't see deafness as a disability. They see being deaf as defining their cultural identity and see signing as a sophisticated, unique form of communication.<sup>1-3</sup> (See box 1 for references on commentaries reacting to this case.)

Zina Emmerson, like her husband and three of her four children, is profoundly deaf. She said: “For me, I would just let it happen naturally. I was happy either way [with my children]. As long as they were healthy. But I can understand why they did it. It's so easy to communicate with your own kids in your language [sign language].”<sup>4</sup>

## Ethics

In the case of Duchesneau and McCullough, there is no ethical issue—the couple have the right to procreate with whomever they want. And many couples with a family history of deafness or disability seek to have a child without that disability.<sup>5</sup> But some deaf couples have expressed the desire to use prenatal genetic testing of their fetus<sup>6</sup> or in vitro fertilisation and preimplantation genetic diagnosis to select a deaf child. These choices are not unique to deafness. Dwarves may wish to have a dwarf child.<sup>7</sup> People with intellectual disability may wish to have a child like them. Couples of mixed race may wish to have a light skinned child (or a dark skinned child, if they are mindful of reducing the risk of skin cancer in countries like Australia).

## Designer babies

Many would see deliberately creating deaf babies as the most perverse manifestation of creating designer

## Summary points

Genetic tests should be offered to couples seeking to have a child to allow them to select the child, of the possible children they could have, who will start life with the best opportunity of having the best life (subject to cost constraints)

Couples should employ genetic tests to have the child, of the possible children they could have, who will have the best opportunity of having the best life (subject to cost constraints)

Couples should be free to refuse genetic testing of themselves or their offspring (provided that their refusal does not harm their child)

Couples should be free to request and obtain genetic testing provided there are sufficient resources and their choices do not harm the child produced or other people, even if this deliberately brings a child into the world with what most people judge to be worse than average prospects

Freedom includes the freedom to do what others disapprove of or judge wrong, provided the exercise of freedom does not harm others

babies.<sup>8</sup> Deafness, they would say, is a disability. Deaf people are denied the world of sound, music, and the most fundamental form of human communication. People who claim that deafness represents a unique culture that can be fostered only by being deaf are mistaken. Hearing children of deaf parents can learn to sign, just as children of English parents can learn to speak Chinese as well as English. It is better to speak two languages rather than one, to understand two cultures rather than one. (It would be disabling for children of English parents living in China if the children spoke only English, even though it might be easier for their parents to communicate with them.)

## Quality of life

Many people believe that doctors should not help couples to have a deaf child. It is important to distinguish between two meanings of “having a disabled child.” Some deaf couples refuse to consent to the insertion of a cochlear implant for a child who is born deaf but who could hear if given the implant.<sup>3,9</sup> Others have even advocated “removing deaf babies

The topic of this article is the subject of a debate in this month's issue of *Journal of Medical Ethics*. Go to <http://jme.bmjournals.com> to read the debate in full

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BMJ 2002;325:771-3

### Box 1: Creating deaf babies—commentaries on this case

Anstey KW. Are attempts to have impaired children justifiable? *J Med Ethics* 2002;28:286-8.

[jme.bmjournals.com](http://jme.bmjournals.com); see Current Controversies.

Levy N. Deafness, culture and choice. *J Med Ethics* 2002;28:284-5. [jme.bmjournals.com](http://jme.bmjournals.com); see Current Controversies.

[bmj.com](http://bmj.com) has links to references discussing equality and disability published in the *Journal of Medical Ethics* ([jme.bmjournals.com](http://jme.bmjournals.com)).



References relating to discussion on equality and disability can be found on [bmj.com](http://bmj.com)

from the homes of their hearing parents, who are not immersed in the Deaf subculture.”<sup>10</sup> Such children would be harmed because they would be worse off (by remaining deaf or unable to speak) than they would otherwise have been (if they could hear or speak).

But what if a couple has in vitro fertilisation and preimplantation genetic diagnosis and they select a deaf embryo? Have they harmed that child? Is that child worse off than it would otherwise have been (that is, if they had selected a different embryo)? No—another (different) child would have existed. The deaf child is harmed by being selected to exist only if his or her life is so bad it is not worth living. Deafness is not that bad. Because reproductive choices to have a disabled child do not harm the child, couples who select disabled rather than non-disabled offspring should be allowed to make those choices, even though they may be having a child with worse life prospects.

## Reproductive decision making

What is the goal of reproductive decision making? We offer genetic tests to couples to allow them to select the child—from the possible children they could have—with the best opportunity of having the best life.<sup>11</sup> Indeed, I have argued that couples have a moral obligation to select the child with the best prospects. For that reason society offers testing for Down's syndrome, haemophilia, cystic fibrosis, and a range of other genetic conditions. But how should we decide what constitutes “the best life prospects?”

In antenatal care, screening for Down's syndrome is now offered routinely. Each couple makes its own decision about whether or not to have a child with Down's syndrome. I believe that, like deafness, intellectual disability is bad. But my value judgment should not be imposed on couples who must bear and rear the child. Nor should the value judgment of doctors, politicians, or the state be imposed directly or indirectly (through the denial of services) on them. The Nazi eugenic programme imposed a blueprint of perfection on couples seeking to have children by forcing sterilisation of the “unfit,” thereby removing their reproductive freedom.<sup>12</sup> There are good reasons to engage people in dialogue about their decisions, to try to persuade them with

### Box 2: The right to choose?

I have said that it is important to give the freest scope possible to uncouth things, in order that it may appear in time which of these *are fit to be converted into customs*. But independence of action, and disregard of custom, are not solely deserving of encouragement for the chance they afford that better modes of action, and customs more worthy of general adoption, may be struck out; nor is it only persons of decided mental superiority who have a just claim to carry on their lives in their own way. There is no reason that all human existence should be constructed on some one or small number of patterns. If a person possesses any tolerable amount of common sense and experience, his own mode of laying out his existence is the best, not because it is the best in itself, but because it is his own mode.

This quote by John Stuart Mill is taken from his book *On Liberty*.<sup>13</sup>

arguments, but in the end we should respect their decisions about their own lives.

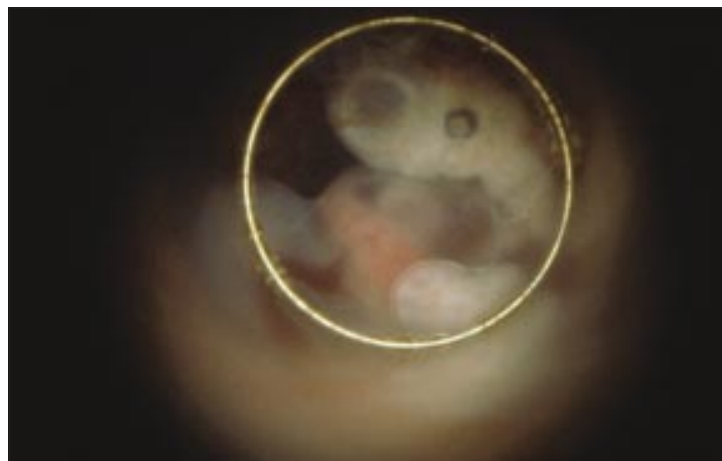
## Why should freedom extend to reproductive choices?

John Stuart Mill, philosopher and radical reformer, argued that when our actions affect only ourselves, we should be free to construct and act on our own conception of what is the best life for us. Mill was not a libertarian. He did not believe that such freedom was solely valuable for its own sake. He believed that freedom was important for people to discover for themselves what kind of life is best. It is only through “experiments in living” that people discover what works. Mill strongly praised “originality” and variety in choice as being essential to discovering what kind of lives are best for people.<sup>13</sup>

Importantly, Mill believed that the lives of some people are worse than others. Famously, he said it is better to be Socrates dissatisfied than a fool satisfied. He distinguished between “higher pleasures” of “feelings and imagination” and “lower pleasures” of “mere sensation.” Mill criticised “ape-like imitation,” subjecting oneself to custom and fashion, indifference to individuality, and lack of originality.<sup>13</sup> None the less, he was the champion of people's right to live their lives as they choose (see box 2).

Reproduction should be about having children who have the best prospects. But to discover what are the best prospects, we must give individual couples the freedom to act on their own value judgment of what constitutes a life of prospect. “Experiments in reproduction” are as important as “experiments in living” as long as they don't harm the children who are produced. For this reason, reproductive freedom is important. It is easy to grant people the freedom to do what is agreeable to us; freedom is important only when it is the freedom for people to do what is disagreeable to others.

We already accept that couples should be free to refuse to employ genetic tests. That is one of the principles behind non-directive genetic counselling. Should scarce resources be devoted to respecting this kind of reproductive freedom? There is a paradox. Either such freedom is important, in which case it



“The child is harmed by being selected to exist only if his or her life is so bad it is not worth living”

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should be supported with taxpayers' money. Or it is not important, and there is no problem with allowing only people with the personal resources to buy it. The only legitimate ground for interference in reproductive decisions would be an important detrimental social impact of such choices. But it is unlikely that many people would make a selection for disability.

### Concluding remarks

Historically, medicine has been used for the prevention and treatment of disease. Of course, that has not been exclusively so. Much cosmetic surgery is aimed at enhancing normal characteristics. And contraception and abortion mostly have nothing to do with disease. But requests to deliberately select a disabled child push respect for autonomy to its limits. Increasingly, people

will seek to use medicine to improve their lives in ways that some may disagree with. And some of those improvements will not be in terms of prevention or treatment of disease, but in the achievement of other goods in life. Will we allow them such choices or offer medicine only on a "doctor knows best" basis?

As rational people, we should all form our own ideas about what is the best life. But to know what is the good life and impose this on others is at best overconfidence—at worst, arrogance.

This article is a development of Savulescu J. The right to play God. *Aust Med* 2002;14:16.

Funding: None.

Competing interests: JS was employed by the Murdoch Childrens Research Institute at the time of writing.

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(Accepted 9 July 2002)

### A memorable patient

#### Ernest

I first met Ernest at the end of a busy surgical clinic. From his pallor and gaunt features I suspected that he might be terminally ill. He looked about 80 years old rather than his real age of 60. He complained of an inability to swallow food, breathlessness, and weight loss. I admitted him for urgent investigation, and an abdominal computed tomogram revealed inoperable gastric cancer with multiple metastases. He deteriorated and was referred for palliative care.

Ernest was an old fashioned sort, well mannered and courteous, quietly spoken, and above all a gentleman. He was single, had lived alone for most of his life, and had no surviving family. His main interests were attending his increasingly rare Air Force reunions and keeping up with old friends—a man content with simple pleasures. We quickly established a rapport, and it fell to me to tell him his diagnosis.

The change was extraordinary. He became confused and aggressive, unaware of his surroundings, confrontational and obstructive at every opportunity. Hypoxia, opiate analgesia, infection, and cerebral metastases were all considered as explanations for his altered behaviour.

On one morning ward round, as we left his cubicle, Ernest asked me to stay. He seemed more lucid and wanted to talk. He realised that his behaviour had changed and was frightened. He accepted death, but one fear remained. He was terrified at the idea of a postmortem examination and wanted his body to be left

alone after he died. I explained that I would issue his death certificate, and a postmortem examination was not required for diagnosis and would therefore not be requested. Ernest was relieved. He became his old self again, a favourite of the staff, and two days later he died.

It is often difficult in clinical practice to identify the foremost concerns of our patients. After his diagnosis, Ernest feared one thing more than death itself. He worried that his body would be cut up after he died, and that he could do nothing to stop it. In my short career, I cannot recall giving a greater consolation to any patient than the guarantee that I gave Ernest, that when he died he could truly rest in peace.

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We welcome articles of up to 600 words on topics such as *A memorable patient*, *A paper that changed my practice*, *My most unfortunate mistake*, or any other piece conveying instruction, pathos, or humour. If possible the article should be supplied on a disk. Permission is needed from the patient or a relative if an identifiable patient is referred to. We also welcome contributions for "Endpieces," consisting of quotations of up to 80 words (but most are considerably shorter) from any source, ancient or modern, which have appealed to the reader.